

Why People with MS are *Really* Leaving Work: From a Clayton's Choice to an Ugly Passage –
A Phenomenological Study
Margaret H. Vickers, Ph.D.
School of Management, College of Business
University of Western Sydney

Abstract: Where some studies have suggested that people with Multiple Sclerosis (MS) may leave a workplace as a result of disease progression, this qualitative study, situated in Australia, found that people with MS might really be leaving work as a result of ugly organizational processes. The influence of discrimination and a hostile work environment on the careers of people with MS seem to have been under-emphasized in previous studies. Two themes are reported that support this contention: that the decision to leave a workplace is effectively a “Clayton's Choice”-- the choice you have when you don't really have a choice -- and “An Ugly Passage.”

Key Words: Multiple Sclerosis; employment; discrimination

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Introduction

Multiple Sclerosis (MS) is one of the most prevalent neurological disorders in the world (Rumrill et al, 1998; Rumrill et al, 2000). In 2001, it was estimated that there were 2.5 million people in the world that have MS. It is also one of the most common chronic illnesses in the Western Hemisphere, affecting as many as 500,000 in the United States alone (Rumrill et al, 1998). In Australia, the National Health Survey of 2001 indicated that there were approximately 15,000 Australians with MS (MS Australia, 2003).

This paper is the first in a series of articles talking about “what is really going on” in the lives of people with MS. I am trying to shine a light on the real story about the life and work of people with MS. As a person with MS myself, I have become increasingly frustrated with and concerned about the literature that is currently available about and for people with MS. It is my contention that the right questions are not being asked and, correspondingly, not being answered.

This paper focuses attention on why individuals with MS might really be leaving their place of work. At first glance, this might seem obvious: MS is a progressive disease; people with MS must leave work because the ravages of the disease force them too. However, I claim that this is not always the case and offer a different perspective.

Literature Review

MS: The Disease

Before understanding the social experiences of people living with MS, it is necessary to understand the physiological dimensions of this experience. MS is an often unpredictable, progressive, degenerative disease of the Central Nervous System (CNS) (Kraft, Freal, & Coryell,

1986; Rumrill, Tabor, Hennessey, & Minton, 1998), which is characterized by damage to the myelin sheath that insulates white matter tracts within the brain and along the spinal cord (Rumrill et al 2000: 109). Kraft (1981, cited in Rumrill, Tabor, Hennessey, & Minton, 2000, p. 109) compared the demyelination process in people with MS as the breakdown of rubberized coating that surrounds electrical wires, and that these breaks in the coating interfere with the transmission of electrical impulses. In people with MS, the slowed or impeded neurological impulses result in uncoordinated or awkward physical responses to their environment (Kraft, 1981).

There are now reported five different disease course “types” of MS: benign; relapsing/remitting; primary progressive; secondary progressive; and progressive relapsing (Australian Multiple Sclerosis Longitudinal Study, 2003 p. 55). For the majority of people with MS – around 70 per cent – the course of the disease is characterized by seemingly random cycles of exacerbations (relapses) and remissions (Rumrill, Roessler, & Cook, 1998, p. 242). Not only is the person with MS unable to predict when (or for how long) an exacerbation will occur, they cannot anticipate with any certainty which symptoms to expect. The uncertainty caused by this cyclic ebb and flow of symptoms, rather than the symptoms themselves, has been argued to be a disruptive influence on virtually every life role (Rumrill, Roessler, & Cook, 1998).

The most common physiological symptom is fatigue (Kraft, Freal, & Coryell, 1986; Rumrill, Roessler, & Cook, 1998; Gregory, Disler, & Firth, 1993; Koch, Rumrill, Roessler, & Fitzgerald, 2001), followed by (in descending order) balance and coordination problems, diminished strength and stamina, motor dysfunction, bowel or bladder dysfunction, visual impairment, depression or anxiety, pain, cognitive difficulties, sexual dysfunction and speech impairment (Koch, Rumrill, Roessler, & Fitzgerald, 2001, p. 157; Rumrill, Roessler, & Cook, 1998). MS can cause problems in virtually every area of physical functioning.

Unseen symptoms, such as those just described, can create great confusion in the workplace, with those around the person with MS often not able to see that anything is wrong, making MS a disease that is almost always confusing and frustrating for everyone exposed to it, including employers (Vickers, 2001). Further, in 90% of cases, onset of the disease occurs between the ages of 15 and 50 years, striking the person during their peak years of education, career development and family life (LaRocca, Kalb, Kendall, & Scheinberg, 1982; Jongbloed, 1998; Rumrill, Tabor, Hennessey, & Minton, 2000). These usually productive years can be disappointing for people with MS; specifically, career development slows and, in many cases, comes to a halt after diagnosis (Rumrill, Tabor, Hennessey, & Minton, 2000, p. 110).

MS and Employment

Disturbingly, the retention of employment for people with MS is even lower than figures for others with disabilities in general, and lower than would be expected even given the presence of a severe physical disability (Roessler & Rumrill, 1994). More than 90% of people with MS have employment histories, with most (60%) still working at the time of diagnosis (LaRocca & Hall, 1990; Roessler & Rumrill, 1994; LaRocca 1995; Rumrill, Tabor, Hennessey, & Minton, 2000, p. 210; LaRocca, 1995). Women are significantly less likely to be employed than are men. In the US, as many as 80 % of women with MS were unemployed compared to 66% of men

(LaRocca, Kalb, Scheinberg, & Kendall, 1985; Rumrill, Tabor, Hennessey, & Minton, 2000). In Canada, the figures are similar: 70% of women and 58% of men with MS were reported to be unemployed (Edgley, Sullivan, & Dehoux, 1991; Rumrill, Tabor, Hennessey, Minton, 2000, p. 111). However, some studies have indicated that as few as 25 or 30% of people with MS are able to retain employment as their illness progresses (Jackson & Quaal, 1991; Roessler & Rumrill, 1994; Jongbloed, 1998: 194; Rumrill, Tabor, Hennessey, & Minton, 2000).

To date, most of the initiatives in response to this concerning phenomenon have placed emphasis on job retention (Sumner, 1995; Rumrill, Roessler, & Cook, 1998), that is, keeping people working who are currently working. However, this approach ignores the majority of people with MS who have successful work records but who are now unemployed, who may have left the workforce voluntarily, and who diminish their chances of regaining employment with every passing day (Rumrill, 1996; Rumrill, Roessler, & Cook, 1998). Once a person disengages from work, several threats to their continuing career success become evident. First, there may be potential disincentives from social security support payments. Second, they may assume the “sick role” which does not encourage a return to independence or work. And third, they may socially detach from former co-workers (Rumrill, 1996; Rumrill, Roessler, & Cook, 1998). What is clear is that those individuals with MS who leave the work force are unlikely to return (Rumrill, Tabor, Hennessey, & Minton, 2000).

People with MS Leaving Work

We know that illness-related predictors of unemployment exist in many people with MS. These have been claimed to include severe physical disability, the presence of visual impairments, ambulatory problems, cognitive dysfunction and a steadily progressive disease process (Rumrill, Roessler, & Cook, 1998). A mixture of impairment and disability, as well as disease course, are predictive of not working (Ford, Gerry, Johnson, & Tennant, 2001, p. 520). Some have claimed that physical limitations and the physical inability to perform job tasks are the most commonly cited reason why people with MS are leaving the workforce (LaRocca, Kalb, Scheinberg, & Kendall, 1985; Rumrill, Tabor, Hennessey, & Minton 2000; Duggan, Fagan, & Yateman's, 1993). Ford and colleagues also assumed that people with MS are not working because of disease progression. For instance, they claimed that having a swallowing impairment – an indicator of disease progression -- increased the odds of not working by 8.7 times (Ford, Gerry, Johnson, & Tennant, 2001).

Along this vein, much of the Occupational Therapy (OT) literature concerns itself with promoting, maintaining or restoring occupational performance – retaining employment based on physical capacities (Jongbloed, 1998). Occupational difficulties tend to be considered from the perspective of individual's abilities and limitations, and on any physical or other barriers on their immediate environment (Jongbloed, 1998). For example, it has been suggested the people with MS could improve their work performance with appropriate workplace enhancements such as job adjustments, environmental and assistive technology, social support and healthful self care practices (Gulick, 1992; Rumrill, Tabor, Hennessey, & Minton, 2000).

However, others have claimed that most of the variation in employment status seems to be due *not* to the severity of the disease or to educational, sex, or other demographic differences

but, instead, to factors such as premorbid personality, coping style, characteristics of the workplace, and social support systems (LaRocca, Kalb, Kendall, & Scheinberg 1982, p. 256). Still others have argued that the capricious disease course – the cyclic ebb and flow of symptoms and disability – are what constitutes the most prominent impediment to adjustment following diagnosis and, thus, the biggest hurdle to continuing employment (Rumrill, Roessler, & Cook 1998).

Roessler and Rumrill (1994, p. 1) confirm that the severe and pervasive impact of multiple sclerosis is *just one* reason for the low rate of post-diagnosis employment. Other authors have pointed the fact that the levels of disability *do not equate directly* or comfortably with the levels of unemployment in people with MS, especially when compared, say, to people with other disabilities in the community (See, for example, Roessler & Rumrill, 1994; LaRocca & Hall, 1990). Physical disability has been confirmed as not being the only, or even the primary, cause of unemployment in people with MS (LaRocca, Kalb, Kendall, & Scheinberg 1982). People with MS often leave work for non MS-related reasons (Rumrill, Tabor, Hennessey, & Minton, 2000, p. 113).

So, while there has been some recognition that people with MS may be leaving work for a variety of reasons that may or may not be directly associated with the disease process and associated disability, what appears to have been largely ignored in the literature is the role of organizations and their processes, including the behavior of employers and managers, including the institutional, political, social or cultural aspects of organizational life. There have been a couple of exceptions: Ketelaer (1993) conducted a study in Belgium and found that employer attitudes and interactions with co-workers influenced employees' willingness to request MS-related accommodations at work. Sumner (1995) identified open communication and the willingness for the employer and employee to understand one another's concerns as key ingredients to successful job retention for people with MS (Sumner 1995; Rumrill, Tabot, Hennessey, & Minton, 2000).

However, there have been no studies that highlight the often brutal aspects of organizational life that may be significant contributors to people with MS leaving work. Prior work by this author in the broad area of living with invisible chronic illnesses has emphasized some of these themes, but specific studies on the working lives of people with MS have not previously been conducted (Vickers, 2001). I posit that, for some people with MS, giving up work is less about physical disability and more about the ugly side of organizational life. I argue that negative social and organizational phenomena, such as stereotyping, discrimination, and over-zealous managerialism may be driving people with MS from their places of employment, either unnecessarily or prematurely.

Methodology

To date, no exploratory, purely qualitative studies of the experiences of people with MS, who have left the full time workforce, have been conducted. There have been studies conducted about people with MS and associated employment issues (Roessler & Rumrill, 1994; Salomone & O'Connell, 1998; Roessler, Fitzgerald, Rumrill, & Koch 2001; Koch, Rumrill, Roessler, & Fitzgerald, 2001; Dyck & Jongbloed, 2000; Bishop, Tschopp, & Mulvihill, 2000; Edgley,

Sullivan, & Dehoux, 1991; Gregory, Disler, & Firth, 1993; Gregory, Disler, & Firth, 1996; Hakim et al., 2000; Jongbloed, 1998; Rao, Leo, Ellington, Nauertz, Bernardin, & Unverzagt, 1991; LaRocca, Kalb, Kendall, & Scheinberg 1982; Roessler & Rumrill, 1995; Rumrill, Roessler, & Cook, 1998; Rumrill, Tabor, Hennessey, & Minton, 2000). However, none of these studies have been situated in Australia, none have been purely qualitative, and none have addressed the reasons why people with MS have left their place of work. Most studies simply assume that it is the disease process or some other physical, psychological or environmental impediment that is the problem – an assumption that I claim is not always accurate.

Heideggerian Phenomenology

I used Heideggerian phenomenology as the methodological vehicle for this study. The goal of Heideggerian phenomenology is to understand everyday practices (Benner, 1985, p. 5). The hermeneutic method outlined in Heidegger's *Being and Time* (1927/1962) proposed a method for the study of sacred texts and, indeed, a means of studying all human activities. It was developed in opposition to Husserl's transcendental phenomenology (Dreyfus, 1991), which requires the researcher to bracket their beliefs and experiences about the phenomenon under review.

Rather than bracketing my experiences, Heideggerian phenomenology accepted, even encouraged, my personal knowledge and experience of living and working with MS. According to Heidegger, the researcher's influence in phenomenological research cannot be underestimated. Indeed, it will determine what phenomena, facts and relations will enter their consciousness (Moss & Keen, 1981, p. 108). The researcher's sensitivity, orientation and perceptiveness will shape the interpretation (Osborne, 1990 p. 85). Heideggerian phenomenology allowed me to operate from an "inside" perspective, which was disclosed to respondents in all relevant documentation. I was aware that my inside status definitely brought with it a special privilege. I would have access, I believed, to special "inside" information:

"While it isn't always true that the "inside" perspective on a person's ... actions is necessarily more charitable, it does operate on different information than does the outside view. The inside information may be more negative than the outside perspective – but whatever the case, it will surely be different. The locus of your information, whether from the inside or outside, is the first central difference in how you attribute meaning to your own behavior compared to how you attribute it to the behavior of others" (Wilmot, 1975, p. 59).

At the time of the interviews, I had had MS for over twenty years, and had experienced varying levels of disability over that time. This brought a perspective and direction to the interviews that would have been lacking from one who had not lived and worked while having this disease. I knew what respondents were talking about for the most part having experienced it, feared it, lived it or, at the very least, read about what they were telling me and considered it as a possibility for my future. I was also able to ask questions that an outsider might shy away from and could encourage frank admissions by pointing to my own circumstances, if necessary. Others have noted that outsiders have difficulty gaining closely held information (Field & Morse, 1985, pp. 118-119). I did not seem to have that problem.

Participants

This qualitative study was not intended to be either representative or generalizable. It was intended to explore a phenomenon that is not well understood – why people with MS are really leaving work. Contact was made with potential respondents through the MS Society of New South Wales. I was invited to contact members of support groups, which included attending meetings to explain the study and recruit potential respondents. I also placed an advertisement in my own neurologist's office, advertising the study and inviting potential respondents to contact me directly.

I interviewed 20 respondents, with a total of 21 interviews being conducted as one respondent was interviewed twice. Interviews ranged from 1.5 hours to 3 hours in duration and were guided by focus areas that shifted as the interviews progressed. Sixteen women and four men participated in the interviews, a reasonable representation of the sex breakdown of the MS population worldwide, which is around 2:1. Ages of respondents ranged from 28 to 65 years, with a mean age of 47 years. In all, there were over 43 hours of interview data, including 35 tapes that were transcribed verbatim.¹ This resulted in 1,222 pages and 335,258 words of transcribed text available for thematic analysis. The study was approved by the University of Western Sydney Human Ethics Review Committee as well as having ethics approval from the Multiple Sclerosis Society of New South Wales. Pseudonyms have been used for all respondents, people and organizations mentioned during the interviews.

Finally, because quite a passage of time had elapsed since conducting the interviews and writing about them, I listened to all tapes again and corrected all of the final transcripts. This was a monumental additional task, but well worthwhile as it enabled me to recreate the details of the interviews in my mind, as if I had conducted them just yesterday.

Results

Why People with MS are *Really* Leaving Work

During this extensive series of interviews, no-one spoke of physical access issues at work hastening their departure, and no-one indicated that they had been unduly depressed or unable to function at work for psychological reasons, either. However, many respondents did state that fundamental support for their disability was not present in their workplaces – even if the policies requiring such support were. Worse, several respondents reported being actively pushed out of their place of work against their will and before such time as their disability precluded their ability to do their job. Below I have reported two themes that emerged from the analysis: “A Clayton's Choice” and “An Ugly Passage.”

A Clayton's Choice

I have written elsewhere about the phenomenon of *Clayton's Support*, which is the “support you get when you are not getting support” (Vickers, 2006b, p. 129). This concept borrows from the advertising campaign for a non-alcoholic beverage called Clayton's, where

consumers were encouraged to indulge in the drink they could have when not having an alcoholic drink. Here, I use the concept of Clayton's once again, but this time in association with choice. I define a *Clayton's Choice* as, "the choice you have when you don't really have a choice."

During the interviews, I heard many of the respondents describe to me just these kinds of choices. Some described having "chosen" to leave their place of work because the situation had become intolerable; that they were being forced out. Others had "chosen" to stay and were tolerating major difficulties and injustices at work because they felt they would be unlikely to get work elsewhere. They perceived widespread employer discrimination against people with disabilities in general and people with MS in particular.

One way in which the choice to leave an organization is really a Clayton's Choice is when pressure is brought to bear on the person with MS to leave, by alienating them or downgrading their duties, by increasing what is expected of them, or by not being prepared to support that person's physical needs in doing their job. Penny spoke of returning to work after she had been [incorrectly] diagnosed with a stroke after what had actually been her first MS exacerbation. After a short period of convalescence, her doctor had said that she could return to her job as a Senior Library Manager at an Australian university. Unfortunately, upon her return, Penny was not allowed to return to her previous duties or to see her staff. She was intercepted on the morning of her arrival:

Penny: I had some problems at work ... Well, what happened when I got back to work [after the supposed stroke], because the neurologist said, "You can go back to work." It was Friday, and he said, "You can go back to work on Monday." So I rang up my employer, the person I was responsible to, and said, "I'm coming back to work on Monday." And I turned up at work, and she actually *raced*, she must have seen me coming in and she raced downstairs to catch me in the toilet before I put my stuff away and went to my department. And I was not actually permitted [to go to her job]. She said, "Come back up with me." ... She took me upstairs and talked to me, and they put me in a room by myself. [Penny is becoming very upset; weeping.]

MV: ... So, she put you in a room on your own?

Penny: Yes. I was given different duties. I was given a "special" job. But I was *devastated* [Starts weeping again].

MV: Yes, I'm sure. So you were the manager of this department at that time?

Penny: Yes, and very close to my staff. [Crying more loudly]. I was just looking forward to seeing them all. [Weeping again] ...

MV: And then she's herded you into a room on your own, is that correct?

Penny: Yes, yes, yes. And I was given a job; it was to do with the procedures for the library, for the University Library. And I was responsible to the personnel-type manager to get this job done. So, they had a procedure manual that was very out-of-date, and they wanted someone to update it ...

MV: And you wouldn't have been in contact with anybody if you were stuck in the corner updating a policy manual?

Penny: No, it was pretty awful actually.

Penny was isolated from her colleagues, her work responsibilities were inappropriately downgraded from senior library manager to policy document editor, and these job responsibilities and location changes were made without appropriate discussion or consultation. Things didn't get much better. After finishing her "special project," Penny found herself a job in another section of the Library where some of the staff also became resentful. One woman actually complained about one of Penny's physical accommodations:

Penny: And things like, I needed a footstool under my desk, and she made a fuss about that.

Penny also needed to take a rest break during the day and would lie down in her lunch hour. She also needed to use the bathroom more frequently than most people. This meant that she had to ask for extra relief from certain demanding tasks, such as being rostered on to the information desk. This also apparently fuelled resentment against her, even though she was able to perform her duties:

Penny: ... I'd ask for rostering for the lunch break to allow me to have an hour for my lunch break. It would have to be rostered; I couldn't do more than a certain time. Or even, say I'd come back from a tea break, and I'd be on the information desk, which is really pressured, but I'd need to go and urinate not long afterwards and that meant I would have to ask someone to come out. And you could tell by the expression that they didn't like it too much.

Unsurprisingly, over time, Penny became increasingly distressed at her workplace. When she visited her neurologist, he immediately recommended that she retire from work. What would be recorded about Penny's departure from her workplace would have been Penny's "choice" to take medical retirement, a choice supported by her doctor. I would argue this was a Clayton's Choice.

Mary, who, coincidentally, also worked in a University Library elsewhere, described her very severe onset of MS, where she was severely incapacitated for some time, and continued to have cognitive and speech problems subsequently. She initially returned to her job on a part time basis, working six hours a week, before increasing this to nine hours per week when she was able. Then she had another attack, and another, in quick succession, which landed her in hospital again for six weeks. At the same time, the management in the library where she worked changed:

Mary: It was fine until this [MS attack] happened again, suddenly. It's always sudden. And then the people, this was the management, they didn't think about me so much [laughing], because they are thinking about their dollars and cents [laughing]. And this new boss, she wanted me to be retired ...

MV: When you came back after that, they wanted you to go?

Mary: Well, they were very nice. They smiled a lot [both laughing] and they didn't want me to go back to work. They came to me, to my place.

MV: Oh, they just didn't want you to come back at all?

Mary: No, that's exactly right ... They didn't want me because they had two people who had died recently with cancer and AIDS, so they didn't want that.

Of interest, Mary never actually returned to work after that episode. Her employers came and saw her at her home to discuss her future, even though Mary believed that she would have been able to return to work on reduced duties. According to Mary, the management where she worked *wanted* her to retire – it was hardly her choice. However, the official outcome would, once again, show the medical retirement of a person with MS -- another unfortunate example of a Clayton's Choice.

Irene reported similar insensitivity at the school where she worked. The new Principal at her school decided to move the staff room to another location giving Irene much further to walk. Irene was a woman in her fifties who had obvious difficulties walking and used a walking stick. It was clear to me that walking up and down steps, or any distance, would have been very difficult for her. However, the staff room was moved without appropriate consultation with Irene, or consideration of her physical disability:

Irene: The first Principal was very supportive ... and then, unfortunately, the Principal changed and ... the new Principal decided to have the staffroom moved across the playground into this building, which was very difficult for me [sounds upset].

MV: Did they talk to you or consult with you about doing, moving that?

Irene: Well, she said to me, "I found this wonderful staffroom but I don't know how *you're* going to manage Irene?" And I said, "Well, all I can do is give it a go," which I did. And at the end of one year I said, "Look this is not working for me." And she said, "Well, we can't take it back," [whispering] and I believed her ... and unfortunately the organizer for the Teacher's Federation, the Union, she said, "Irene, be very careful. If you make too much fuss, they may retire you." So I was really frightened. But after a year I just decided it was too much, and I just went and said to her, "Look, I cannot cope with this."

MV: How far across did you have to walk to get to the staffroom?

Irene: Well, it was down eleven steps. All up, eleven steps if you were coming back and across [Irene indicates a distance of about fifty meters]. So I mean it was a playground, not a huge playground, but a playground.

MV: Quite a distance for someone...

Irene: Absolutely, with a walking stick.

Even though the Principal had "asked" Irene about the decision to move the staff room, the decision had already been made – another Clayton's Choice. For Irene to have objected on the basis of her obvious physical disability would have required her to resist what all the other able bodied staff had already approved. I also point, with concern, to Irene's remarks about her future employment and the union representative's warning to her not to "make too much fuss." Irene found herself working in an intolerable situation, and fearful for her job. Her choice to say nothing for that twelve months was a Clayton's Choice.

An Ugly Passage

In addition to being presented with Clayton's Choices several respondents spoke of what I have described as their ugly passage away from their employment, post-diagnosis. Both

Miranda and Jason were convinced that once their employers learned that they had MS, they tried to get rid of them. Jason reported being “counseled out” of his workplace and being given higher targets after disclosing his illness. However, it all started with Jason being reassured that there wouldn’t be a problem. One of his colleagues rang him while he was off sick from work, just around the time he learned of his diagnosis:

Jason: ... A bloke from work phoned me up, *nominally*, to see how I was, and I was, “Oh, I’ve probably got MS.” And it was, “Oh, gee. That is awful. We’ll do everything we can to support you. Don’t worry, it’s not a problem.” That lasted about a week ... He must have spoken to the owner of the company, and all the rest, and they’d probably worked out that this could cause them a problem, because they weren’t a huge company, and so everybody had to do everything, and you certainly had to do, fulfill the expectations of the job. There weren’t enough people at that level to carry me.

MV: At that point then, you were still having visual difficulties and a little bit of dexterity. Anything else?

Jason: No. At that time, I’m just thinking [pause]. No ... And, you know, I was, I was trying all the time to *not* create an opportunity for the constructive dismissal, but that was very much what was happening.

MV: ... What happened after you told them [about the diagnosis]?

Jason: Basically, they start to change my targets that I had to meet.

MV: What, higher?

Jason: Yes, and starting to require more. “We’ve decided we want to expand a little bit into other areas. We want you to take this on.” So there was more to do. The sales targets that were set were being increased.

MV: Were they being increased for everyone, or do you think it was just for you?

Jason: They were *nominally* for everyone, but the way they were structured I felt they were, of course, paranoia -- but just because you’re paranoid doesn’t mean they’re *not* out to get you -- and so I thought it was for me. Because other people, if they didn’t make their targets, they just did what we’d all done previously: “Well, sorry, boss, I didn’t make the targets.” ... Because I also knew that they could *not* get rid of me because I’d got MS. But they can get rid of me if I don’t do the job ... So, you know, knowing that added to the stress that I was experiencing.

MV: And what about their general demeanor and behavior towards you? Did it change?

Jason: Yes, in that it [pause]... they started to be more pedantic about things.

MV: Really scrutinizing?

Jason: Absolutely, yes.

MV: And you felt that the scrutiny wasn’t the same for everybody?

Jason: That’s right. And I knew that if I was being scrutinized, very closely, there were always going to be things that you could tick off. “Well, you’re not doing this.”

MV: They can *always* find something.

Jason: Anybody can.

What Jason describes would appear to be obvious discrimination. The rules might have been the same for all, but they were applied differently to him. He also reported having his work

subjected to excessive scrutiny, a common bullying and victimization strategy. Jason ultimately resigned -- a Clayton's Choice -- even though he reported still being able to do his job. It was the deliberate changes of targets designed to make him fail that ultimately resulted in him being counseled out of his job.

Miranda had a similar experience. She made the mistake of sharing, in confidence, news of her illness to a fellow flight attendant where she worked. She then found that, suddenly, after over ten years as a flight attendant, there were reports being written about Miranda's poor work performance when for the past decade there had been none. As with Jason, the bullying and discrimination used to try and get Miranda to leave was being disguised as a legitimate organizational process (see other examples, Hutchinson, Vickers, Jackson, & Wilkes, 2005):

Miranda: ... Like the managers would say, "We are concerned for you as welfare, a duty of care." They would rip me out of the sky for any report that was written. This happened once, this happened twice, and this happens three times. I've got copies of all of them where this happened. The fourth time I saw the [employer's] doctor ... and he said to me, ... he was checking me and whatever, and I said, "Doctor Smith, I've got a limp and I'll show you. Here it is," because my left leg is weak. And I said, "The day I can't take my peers and passengers out of that air craft, I'll be telling you I'll be going". He said, "Miranda, I know," he said. "You are the talk of the town in the company now, because you've got MS and it's just, you know how [employer] is, when they start the rumors." And he said, "Would you agree to an ergonomics testing? The company pays a lot of money to do it."

MV: Is this to test to see if you were still fit to fly, is that right?

Miranda: Yes. I agreed with that. It took about two months to get the results. I ended up going downhill, like that [she indicates with her hand a steep downward slope]. And pretty much the first trip back and I never flew after that.

MV: Do you think the stress affected that?

Miranda: Yes. Oh, *for sure*. But to prove that was so hard. Because you are talking about these people with *top* doctors, *top* lawyers, you know, and I did take it to the Union lawyer. I did take it to another lawyer and they looked at it and they said to me, "OK. It's 30, 40 thousand dollars. It will pay off a little bit off your mortgage. Is it worth it?" ... And I just looked at it and thought, "No."

Employers who wish to divest themselves of employees they don't want *can* be in the driver's seat in such situations, especially if the employee is emotionally, physically and financially vulnerable (Vickers, 2006a). Miranda and Jason were both financially vulnerable, their health was deteriorating, and neither could readily afford a lawyer to defend them, nor did they need to endure the additional stress that would result from the process that would most likely exacerbate their disability further. Miranda told of false reports being written about her, claiming she was unable to do her job. She felt that this was the beginning of a well orchestrated process to get rid of her, even though, at that time, she felt that she could fulfill her duties as required.

Miranda: I thought, "This is the way the Company wants me out. This is how they are going to find a way to discriminate against me, make me sign on a dotted line."

They'd probably prefer to see the back of me. I thought, "Yep. This is the way the Company's going to do it.... It's going to look like if they are *not* discriminating and they're doing the right thing." And yes, *extremely stressed*, and knowing I had a mortgage to pay off ... And it was like, "Oh, my God, I'm going to lose my job!" And so panic, scared ... and I just had no idea what they were going to do ... I was yes, really scared. I thought, "I'm out of here now. This is the way the lovely Company's going to get rid of me."

Discussion

Some respondents reported working in intolerable conditions as a result of employers learning of their illness and making things difficult. Others found themselves leaving work when presented with a Clayton's Choice. Others were simply unable to adequately defend the discriminatory and victimizing processes used to push them out.

The field of vocational rehabilitation has (so far) been unable to make an impact on understanding the troubling phenomenon whereby people with MS are prematurely leaving the workplace (Rumrill, Tabor, Hennessey, & Minton, 2000, p. 116). It is held that with continued emphasis on strategies such as job modifications, provision of new equipment, and job restructuring, people with disabilities can perform their usual work activities in a full time capacity for longer periods of time (Roessler & Rumrill, 1995). However, employer support of the accommodation process has been recognized to be critical to the job retention of people with disabilities (Roessler & Rumrill, 1995).

Unfortunately, what has been presented here is evidence that, sometimes, employer support is not forthcoming. Indeed, not only is the situation not positive, or even neutral, but that darker organizational tactics such as bullying and discrimination are invoked deliberately to the detriment of the person with MS. There is evidence here that people with MS are being pushed out before they needed to be. I would also argue that legitimate organizational processes are being used to expedite such premature workplace separations. This requires further investigation.

It is imperative that researchers consider the results of this exploratory work. I claim that one unexplored reason why people with MS are leaving work prematurely is because of socially constructed assumptions that attach to disability in general, and to MS in particular. We have known for a long time that stigma attaches to illness and disease (Vickers, 2000; Vickers, 2001) with potentially deleterious outcomes for the subject of that stigma, both personally and professionally. In an environment of increasing managerialism and economic rationalism (Vickers, 1999) workers, especially managers, are often implicitly encouraged to be insensitive to the needs of people with disabilities, especially those who have a highly stigmatized illness, even though legislation exists that requires a contrary outcome (for example, Disability Discrimination Act, 1992). At the very least, there are mixed messages for managers who are legally required to make provision for people with disabilities.

While I acknowledge the existence of anti discrimination legislation around the world (for example: Americans with Disabilities Act [ADA], 1992; Disability Discrimination Act [DDA – Australia], 1992; Disability Discrimination Act [DDA – UK], 2005), perhaps it is a

mistake to assume that because the laws are there employers will always adhere to them. Certainly, several respondents indicated their faith in these laws, as does much of the literature pertaining with employment difficulties for people with MS. The uncritical assumption appears to be that, because these laws are in place, discrimination against people with disabilities can no longer happen (see for example, Duggan, Fagan, & Yateman, 1993; Roessler & Rumrill, 1995, p. 10; Roessler & Rumrill, 1994, p. 3; Rumrill et al, 1999; Rumrill, Tabor, Hennessey, & Minton, 2000; Huebner, 2000, p. 14). However, as already noted, people with disabilities are already likely to be more financially vulnerable than most. It is unlikely that they will take on the might of a large, well financed organizations with highly paid company lawyers experienced in litigating such cases in the interests of protecting the organization – and employers know this. As long as the burden of proof remains with victims of discrimination, the stress and expense of court cases is likely to provide a strong incentive for people with MS *not* to litigate, especially when the likely payouts are relatively so small (Vickers, 2006a).

In light of the qualitative evidence presented above, it is surely time to reconsider the plight of people with MS in an effort to keep them employed, or at least, employed for longer. Here is evidence that some people with MS leave work – apparently voluntarily -- because their employers have made it impossible for them to continue.

Margaret Vickers, Ph.D., is Associate Professor and Director of Research, School of Management, College of Business, University of Western Sydney, Sydney, Australia. She has researched many aspects of workplace adversity: bullying in the workplace, being made redundant, living and working with unseen chronic illness, caring for a child with disability while working full time, emotions in the workplace, and living with mental illness. She is the author in excess of 90 international refereed publications including her research books *Work and Unseen Chronic Illness: Silent Voices* (Routledge, New York and London, 2001) and *Working and Caring for a Child with Chronic Illness: Disconnected and Doing it All* (Palgrave MacMillan, London, 2006), London. Professor Vickers is Co-Editor of the *Employee Responsibilities and Rights Journal*, and an editorial/international advisory board member of *Review of Disability Studies: An International Journal*, *Qualitative Research in Organizations and Management: An International Journal*, *Administrative Theory & Praxis* and the *International Journal of Action Research*. She can be contacted via e-mail at m.vickers@uws.edu.au.

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Endnote

¹ There was just one tape that was not transcribed. For the first time in 13 years of conducting research interviews, I didn't believe that this respondent was telling the truth. She did not appear to understand many aspects of having MS, described some symptoms I thought to be highly unusual (unbelievable?), and didn't know anything about any of the medications that are being routinely prescribed. The interview just did not ring true. After consultation with the MS Society, I elected not to include this data in my study.

